

BETWIXT AND IN-BETWEEN STATE AND COMMUNITY:

Illness identities and the distinct expertise of a health-orientated community-based organisation within the contemporary socio-political environment

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This thesis is presented in fulfilment of the requirements for the degree of

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## **CERTIFICATE OF ORIGINAL AUTHORSHIP**

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Signature of Student:



Date: 5<sup>th</sup> March 2013



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## **ABSTRACT**

This thesis is concerned with the critical potentials and challenges of a health-orientated community-based organisation within the contemporary socio-political environment. Hepatitis C (HCV) community-based organisations (CBOs) are reported by government to be a fundamental component of Australia's national response to the HCV epidemic. This is said to be due to a "specific" expertise that mark them distinct from public (health) sector sites. Traditional thinking on what marks civil society organisations like CBOs as distinct is commonly presented in terms of rationalist/utilitarian human service models. This thesis contends that health-orientated CBOs complicate this thinking as people who engage with HCV CBOs do so not only for service access, but also for social and identity reasons to help, and learn from, others to gain answers to questions such as; "who I am?", "whom am I connected to?" and "who can I hope to become?" as a result of HCV.

Drawing from HCV CBO text and interviews with key informants and people affected by HCV, this thesis investigates and links questions of illness experience and distinct expertise of a HCV CBO. Findings are assessed and articulated according to the model developed. Particularly, Victor Turner's work on liminality, which underpins the model, is used to interpret findings. Liminality, referring to a position or status that is "betwixt and in-between" (Turner, 1969), is applied in two different ways: as a negative effect when viewed in the context of illness identities and productively in terms of CBOs.

It is illustrated how HCV lived experience can represent a liminal identity fostered by dominant narratives of HCV that encourage people to adopt medicalised and

health consumer identities. The study also explores how a HCV CBO's relational position in-between state and "community" endows it with a liminal quality that is expressed through the multiple and at times opposing HCV narratives that a HCV CBO (re)produces. Some of these narratives correspond to dominant medicalised and health consumer identities; others present as alternative identities whereby social, cultural and political contexts emerge. The critical potential of a CBO's liminal position, which is purported to underpin its distinct expertise, is discussed by presenting how participants affected by HCV scrutinise and draw from both dominant and alternative HCV narratives in ways that construct identities that are responsive to an individual's particular social circumstances and for some, more "community" minded. However, findings also suggest a CBO tendency to "manage" and marginalise alternative narratives and identities thus threatening its distinct expertise. This tendency is interpreted by discussing the contemporary socio-political climate which CBOs find themselves. This thesis contributes to new understandings of health-orientated CBOs based on a capacity to mediate illness identities in responsive ways, ways that may also give rise to health related social and political understandings and influence.